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CONTENTS

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ORIGINAL ARTICLES

HIV status disclosure among people living with HIV/AIDS at FASO, Mutare, Zimbabwe

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Abstract

Objective: To examine the prevalence, patterns and reasons for disclosure of HIV status among people living with HIV/AIDS.
Design: A descriptive cross sectional survey
Setting: Family AIDS Support Organisation (FASO), Mutare, Zimbabwe.
Subjects: A random selection of members of FASO attending clinic or meetings.
Outcome Measures: Disclosure of HIV seropositivity to sexual partner, to one or more family members, to health care workers and to the wider public.
Results: There was 79%, 72% and 70% disclosure to the family, health workers and to sexual partners respectively. While public disclosure was 23%, more people wanted to disclose but did not get an opportunity. Main reasons for disclosure to family were to obtain psychosocial and material support; to the public it was to give HIV/AIDS a face; and to the sexual partner it was to have safer sex. Knowing one's HIV status for a year or longer was significantly associated with disclosure to family, sexual partner and the public. Females were significantly more likely to disclose to family members compared to males (p=0.004). People in abusive relationships were significantly less likely to disclose to sexual partners (OR=0.17, p=0.039).
Conclusion: Though disclosure rates were generally high, attention must be given to the small number of people engaging in high-risk behaviour, and disclosure counseling needs to be enhanced. Domestic violence hindered disclosure and we advise that it must be prevented.

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Introduction

Zimbabwe had more than 1.3 million people living with HIV and AIDS with an adult prevalence rate of 14.6% by the end of 2007.[1] The stresses associated with discovering that one is infected with HIV include dealing with the possibility of a long debilitating illness; an early death; loss of income; disruption of family relationships; stigma and discrimination. For people living with HIV/AIDS (PLWHA), receiving social support related to living with the infection requires disclosing one's HIV status to significant others.[2] Family, friends and caregivers can provide support to cope with HIV care and medication. The National HIV/AIDS Policy in Zimbabwe recommends "shared confidentiality", which encourages individuals to disclose their HIV status to those who have critical reasons to know.[3] Transmission of HIV in Zimbabwe is predominantly heterosexual and most adults who learn that they are HIV positive remain sexually active.[4,5] Disclosure to partners can help couples to practice safer sex and reduce risk of re-infection.[4,6] In Zimbabwe fear of HIV status disclosure can result in undue pressure to have children, and also reduces access of female PLWHA to abortion services.[4]

Issues of disclosure can have barriers that are rooted in cultural values, and any practice guidelines have to take this into consideration.[7] HIV/AIDS messages and

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strategies have been urged to focus on local determinants of behaviour.[8] Scanty information is available on the prevalence and patterns of HIV status disclosure in Zimbabwe. Local studies in HIV status disclosure and other issues are needed in order to formulate messages with local content for critical programmes such as PMTCT, opportunistic infection (OI) therapy, antiretroviral therapy for PLWHA, AIDS Clinical Trials and Home Based Care.

FASO (Family AIDS Support Organisation) is a support centre for PLWHA in Mutare, the third largest city in Zimbabwe. It offers services in counseling, psychosocial and material support, skills development, clinic and start-up capital for income-generating projects. It has an overall membership of 1 560, but only 200 are currently active and attend the various activities offered at the centre. FASO now has branches in various centres of the Manicaland Province. Counseling at FASO is provided by peer counselors, under the supervision of a nurse counselor.

Materials and Methods

A descriptive cross sectional design with an analytic component was used to study PLWHA members of FASO. The study objectives were to examine the prevalence, patterns and reasons for disclosure of HIV status among PLWHA. The primary outcome was disclosure of HIV seropositivity to sexual partner, to one or more family members, to health care workers and to the wider public. These levels of disclosure were not mutually exclusive, so that a study subject with the outcome of disclosure to sexual partner could also have the outcome of disclosure to family. The variables assessed as correlates included socio-demographics; time since HIV diagnosis; presence of symptoms; history of illness since HIV infection; history and frequency of disclosure counseling; history of domestic violence and use of condoms. Information was also sought on reasons for disclosure or non-disclosure. Ever having been offered help by a counselor to disclose status to someone was used as a proxy for high quality disclosure counseling. For PLWHA in sexual relationships, ever having received couple counseling was used as a proxy for high quality disclosure counseling.

Questionnaires and focus group discussions were used to collect data from FASO members. Simple random sampling, using a table of random numbers on members attending weekly meetings or the FASO clinic was used until the required sample size was achieved. Only HIV seropositive individuals aged 18 years or older and had known their status for at least six months were recruited. To maintain the name and signature of the participants confidential, informed verbal rather than written consent was obtained. Names and other personal identifiers of study participants were not recorded. Data was entered and analysed using the Epi Info 2002 computer software package.[9] Descriptive analysis was conducted using frequencies. Pearson's Chi-square test was used to measure significant relationships. Comparisons for which p values were below 0.05 were considered statistically significant. Qualitative data was analysed manually.

Results

A total of 77 individuals were enrolled between July and August 2004. Characteristics of the sample population are presented in Table I. The majority were female, widowed, tested at FASO, had received high school education and survived mainly on income-generating projects. Of the 21 married or cohabiting participants, seven were in a polygynous relationship. Seventy one of the 77 study participants (92%) were members of a religious group. Seventeen (24%) had disclosed to at least one church member, mainly to join an HIV/AIDS support group run by the church, or to receive food rations. Five (6%) of the participants had not told anyone their status.

Table I: Characteristics of the study subjects.

Characteristics	Frequency	
	N	%
Disclosed to someone in the family	61	79
Disclosed to the public	18	23
Age:		
Mean years (SD)*	36	(9.0)
Less than 35 years	39	51
35 or more years	38	49
Sex:		
Female	64	83
Male	13	17
Education:		
High school	52	68
Primary school	25	32
Marital status:		
Widowed	41	53
Married/cohabiting	21	27
Divorced/separated	12	16
Single	3	4
Time since HIV test:		
Mean years (SD)*	3	(2.9)
6 months - 2 years	44	57
3 - 4 years	20	36
5 or more years	13	17
Main source of income:		
Income generating projects	63	82
Formally employed	9	12
Other relatives' support	2	2
Where received VCT:**		
FASO	53	68
New Start Centre	17	22
Hospital/Clinic	5	7
Other	2	3

SD=Standard deviation. **VCT=HIV Voluntary Counselling and Testing.

Disclosure Patterns

Knowing one's HIV positive status for longer than one year was consistently significantly associated with disclosure in all the three groups, family (a 9.6 times likelihood to disclose status to a family member, 95% CI=2.44, 37.60), sexual partner (95% CI=1.37, 26.1) and significant others (95% CI=1.95, 26.11). A total of 61 (79%) had disclosed to at least one family member (Table II).

Table II: Disclosure to family and to the public.

Characteristics	Disclosed to Family		OR	p	Public disclosure		OR	p
	Yes	No			Yes	No		
Sex:								
Female	55	9	7.1	0.004	16	48	1.83	0.365
Male	6	7			2	11		
Age:								
35 years or more	32	6	1.84	0.433	9	29	1.03	0.836
Less than 35 years	29	10			9	30		
Level of education:								
High school	40	12	0.6	0.346	13	39	1.33	0.429
Less than high school	21	4			5	20		
Time since HIV test:								
More than 1 year	42	3	9.57	0.001	16	29	8.27	0.002
Up to 1 year	19	13			2	30		
Disclosure counseling?								
At least once	55	14	1.31	0.528	17	52	2.29	0.397
Never received	6	2			1	7		
Had hospital admission?								
Yes	14	1	4.47	0.122	5	10	0.55	0.244
No	47	15			13	49		
Has had TB?								
Yes	21	4	1.58	0.346	6	19	1.05	0.843
No	40	12			12	40		
Has had *Herpes zoster*?								
Yes	24	4	1.94	0.223	6	22	0.84	0.980
No	37	12			12	37		

Females were 7.1 times more likely to disclose their status to a family member, with the difference being statistically significant (95% CI=1.95, 26.11). About 40 participants reported that they were in a sexual relationship. Twenty eight (70%) of these had disclosed to their partners, while 12 (30%) had not. The main reasons were to have safer sex and to encourage partner VCT. Reasons for nondisclosure were fear of rejection and of conflict (Table III).

Table III: Disclosure to sexual partner.

Characteristic	Disclosed N (%)	Did not disclose N (%)	OR	p value
Sex:				
Female	20 (71)	9 (75)	0.83	0.570
Male	8 (29)	3 (25)		
Age:				
> 35 years	11 (39)	7 (58)	0.46	0.446
< 35 years	17 (61)	5 (42)		
Time since HIV test:				
> 1 year	21 (75)	4 (33)	6.00	0.017
Up to 1 year	7 (25)	8 (67)		
Ever received couple counseling				
Yes	6 (21)	0 (0)	-	0.098
No	22 (79)	12 (100)		
Condom use?				
Yes	21 (25)	8 (67)	1.50	0.430
No	7 (25)	4 (33)		
Type of relationship:				
Abusive	3 (11)	5 (42)	0.19	0.039
Non-abusive	25 (89)	7 (58)		

Eighteen (23%) had disclosed their status publicly. Reasons given for publicly disclosing included to demonstrate that one could be infected with HIV and yet still look healthy, to encourage VCT uptake and to promote positive living. Among the 59 participants who did not publicly disclose, 32 (54%) had not found an opportunity to do so. Others feared stigma, or had not disclosed to their partner or family. There were 39 participants who had consulted a clinic or hospital other than at FASO and 28 (72%) of these had disclosed to health care workers.

Disclosure Patterns Specific to Family

The most frequent reasons reported for disclosure to family was to receive psychosocial and material support (61%), to help the family understand the illness (51%), to receive material support (36%) and to help family members take up Voluntary Counselling and Testing (VCT) (12%). Three (5%) reported rejection and stigma resulting from their disclosure to the family, while the rest reported no adverse outcomes. The main reasons for non-disclosure were not being ready for it and fear of rejection. Sisters, followed by mothers, then brothers were mentioned the most as family members to whom disclosure had been made. There was no significant association found between disclosure and symptomatic HIV or prior HIV related hospital admission.

Specific Disclosure Patterns to Sexual Partner

Participants in an abusive relationship were significantly less likely to disclose compared to those in a non-abusive relationship (95% CI=0.03, 0.88). Sexually active participants, 29 (72%) reported using a condom at the last sexual intercourse, the reasons being to protect the partner and self. The main reasons for non-condom use were partner refusal and wanting a baby. Four participants neither disclosed to their partners nor used condoms. Twenty four (60%) did not know the HIV status of their partner, while 12 (30%) and four (10%) had HIV positive and HIV negative partners respectively. Only six (15%) had ever received HIV counseling together with their partners. Eight (20%) reported physical abuse within their relationships.

Disclosure Counseling

Sixty nine of the 77 participants (90%) reported having received disclosure counseling, while eight (10%) never had. Of the sixty nine, 35 (51%) had done so once only, with 34 (49%) receiving it on more than one occasion. Only three (4%) of the participants reported ever having been offered help by a counselor to disclose their status to someone else.

Discussion

Disclosure to Family

The high disclosure rate to family is comparable with the 74% and 83% found in previous studies.[12,13] Studies have shown that social support from significant others was significantly associated with disclosure of HIV status.[12-14] At the same time social support for psychological adjustment to live with HIV infection has been found to be one of the benefits of disclosure.[4,12,13,15-17] Like in previous studies in Zimbabwe, relatives were confided in both for emotional and material support, while mothers and sisters were the most likely family members to be disclosed to.[4,13] Female family members have been found to be most supportive and tolerant of HIV infected individuals.[18] While previous studies in Zimbabwe and Ghana found that 40% and 25% of the PWHA respectively had not told anyone about their illness, our study found only 6%.[19,20] Because almost everyone in Zimbabwe now knows someone who has had AIDS, stigma might be reducing, and disclosure becoming easier.[15] Also, the quality of counseling in a support group is higher compared to the home-based care clients in the Woelk study. That females were more likely to disclose to family than males probably reflects the socio-economic dependency of women on others in society, and the need for them to disclose in order to obtain psychosocial support.

Our results concur with previous findings that length of time since HIV diagnosis is associated with disclosure.[4,21] A longer time means more time to deal with the stresses of coping with the diagnosis and obtain skills to disclose. Our study did not find any association between presence of symptoms or prior hospital admission with disclosure, although previous studies have found that some PLWHA delay disclosure until their disease has progressed.[4,22] This might be because our study enrolled ambulant PLWHA, and that TB and Herpes zoster, which we used as proxies for symptomatic HIV, occur relatively early during the course of HIV infection.

That fear of rejection was stated as a reason for nondisclosure and that some participants actually reported experiencing it concurs with findings that rejection and stigma have been reported as risks of disclosure.[4,14,23-25]

Disclosure to Sexual Partner

Our 70% rate of disclosure to sexual partner was much higher than the 50% found in earlier studies in Zimbabwe.[4,19] The rates were also higher than found elsewhere in sub-Saharan Africa.[14,25-28] That people disclosed to partners mainly for protection of their own and partner's health concurs with previous findings in Zimbabwe.[4]

While it makes sense that more time since HIV diagnosis was significantly associated with an increased likelihood to disclose to the sexual partner, concern must be raised that this delay may increase partner exposure to the virus. Past studies in Africa have also found that prevalence of disclosure to sexual partners increased with time since diagnosis of infection.[14,26,27] That a history of physical or sexual abuse was a correlate of disclosure to a partner conflicted with findings from another study.[23] This might be because the majority of participants in our study were women, and in developing countries the victims of domestic violence are usually women. It is worrying that 20% of sexually active participants experienced domestic abuse, and that fear of conflict and violence were reasons for non-disclosure. Domestic violence has been found to be a risk of disclosure, especially when the woman is the first to be tested as being HIV positive.[17,25,29] This situation is not uncommon in Zimbabwe, with the expansion of PMTCT programmes.

Of concern are the 30% HIV positive participants who did not disclose to their sexual partner. An argument that has been used is that PLWHA may opt not to disclose their positive status to sexual partners, but instead practise safe sex.[23,30] However, research has shown that nondisclosers are not more likely to regularly use condoms than disclosers.[23,24] In any case, in Zimbabwe women have little control within their sexual relationships.[31] Also, condom use and other safe sex strategies are not 100% effective, and therefore an ethical responsibility to disclose HIV infection to sexual partners still remains.[24]

Other Types of Disclosure

Contrary to a Zimbabwean study in which no one disclosed to the community at large, our study found 23% disclosure to public.[4] Disclosure to the wider public is good for advocacy and it reduces stigma.[21] The Greater Involvement of People Living with HIV/AIDS (GIPA) principle recognizes that PLWHA help to personalise the epidemic and make an impact on the response to HIV among the wider public, politicians and policymakers.[32,33] Recent gestures by public figures such as parliamentarian and other celebrities in Zimbabwe may have encouraged more people to publicly disclose. That some people wanted to publicly disclose but did not get the opportunity to do so shows that public disclosure rates were underestimated. The few churches that are providing spiritual, psychosocial and material support must be commended. A multidisciplinary approach is the way forward with HIV.

Disclosure to health workers is necessary to facilitate access to care. It is sad that nurses were viewed as discriminatory of PLWHA, and this might compromise disclosure to health workers. Nurses have a pivotal role to play in reducing AIDS stigma by role-modeling a compassionate attitude towards PLWHA.

Disclosure Counseling

That 10% of the participants received no disclosure counseling, and only three people were offered practical help with disclosure is worrying. Research

has shown that as much as 50% of healthcare workers might not be discussing the topic of disclosure with their PLWHA clients.[17,34] In one study, only 46% of the sample reported that a health care provider had offered to help them disclose.[17] Couple counseling is beneficial but is rarely reported.[4] The four participants who neither disclosed to their partners nor used condoms show that it is a small proportion of people engaging in high-risk behavior who are responsible for spreading the epidemic. Healthcare workers have an opportunity to discuss disclosure and safe sex when they communicate test results. Timing is important if we are to avoid further spread of the epidemic. More in-depth patient/provider communication is critical, and barriers and facilitators to this communication should be identified. A qualitative study in Mutare showed that counseling given once was not effective, but continuous counseling to deal with the various aspects of coping with the diagnosis at the various stages of HIV infection is needed.[35]

Conclusion

The findings show that the majority of PLWA disclosed their status to family, sexual partners and to healthcare workers. The major reasons for disclosure to family were to obtain psychosocial and material support; to the public it was to give HIV/AIDS a face; and to the sexual partner it was to have safer sex. Disclosure generally becomes more likely the longer one lives with the HIV diagnosis. Disclosure is critical in many HIV intervention programmes and should be encouraged. Domestic abuse is associated with non-disclosure and should prevented. Disclosure to the public gives HIV/AIDS a face and should be encouraged. There is room for improvement in the quality of counseling provided to people living with HIV/AIDS. Attention needs to be given to the small number of people engaging in high-risk behaviour and spreading the epidemic.

Limitations

The study relied on self-reports to assess rates of and may have overestimated disclosure, and underplayed the adverse effects of disclosure. Prior attendance to a support group has been found to be a predictor of disclosure.[14] It was not possible to draw causal inferences from a cross sectional study. Our study participants were all members of a support group and caution should, therefore, be taken before generalising the findings to the general population. Recall bias on the frequency and quality of disclosure counseling may have affected our findings, especially in those participants who had lived with the HIV diagnosis for several years.

Recommendations

The study recommends the following:

1. The FASO management and AIDS and TB Unit in the Ministry of Health and Child Welfare were advised to engage behavioural scientists to come up with strategies to help health workers and peer counselors to deal effectively with disclosure issues.
2. The Ministry of Health and Child Welfare was advised to include attitude towards PLWHA and HIV disclosure counseling in the training curriculum of nurses.
3. FASO and other counselors in general were advised to encourage and practice couple counseling as an aid to disclosure.
4. Counselors need to be trained to ask about, deal with or appropriately refer issues of domestic violence.
5. FASO management needs to review the scheduling of members for outreach activities so that many get chances to give public testimonies.
6. A similar study that is population based is strongly recommended.

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